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Joined-up data for better decisions: Guiding Principles for Data Linkage

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Guiding Principles for Data Linkage

Our vision for the future is one where evidence of what works in delivering positive outcomes for all of Scotland is delivered quickly and efficiently with minimal burden on front-line services. By improving the ethical and legal governance arrangements, and the technical capacity to securely and efficiently link statistical data, we will enable the research needed to inform policy decisions and Scotland will be recognised the world over as a hub of innovative and powerful statistical research, attracting investment and job creation.

The Data Linkage Framework for Statistics and Research aims to

- 1. build on existing successful programmes collaboratively to create a culture where legal, ethical, and secure data-linkage is accepted and expected;**
- 2. minimise the risks to privacy and enhance transparency, by driving up standards in data sharing and linkage procedures;**
- 3. encourage and facilitate full realisation of the benefits that can be achieved through data-linkage to maximise the value of administrative and survey data.**

In order to support data custodians, researchers and other stakeholders in taking decisions about safe and effective linkage within this new culture, the foundation stone of the Data Linkage Framework is this set of Guiding Principles for data custodians, researchers, ethics or privacy committees, and others involved in data sharing and linkage in taking decisions about safe and effective linkage. Further work to collate good practice examples of the principles being put into practice will be conducted, and a Privacy Advisory Service will be established (see 'Joined-up data for better decisions: a strategy for improving access and analysis', published at www.scotland.gov.uk/StrategyforImprovingDataAccessandAnalysis).

The Principles are heavily based on principles developed for [The Scottish Health Informatics Programme](#) (SHIP) by Professor Graeme Laurie and Nayha Sethi at the Edinburgh Law School, University of Edinburgh. The SHIP principles were adapted to be applicable to wider statistical and research data linkage activities and consulted on in *A Scotland-wide Data Linkage Framework for Statistics and Research: Consultation Paper on the Aims and Guiding Principles*. In addition, the approach and a summary of the principles were tested with members of the public through a deliberative research project. Details and results of the consultation and research are available through <http://www.scotland.gov.uk/Topics/Statistics/datalinkageframework>

We are grateful to Professor Graeme Laurie and Nayha Sethi, to all those who responded to the consultation and to the members of the public who gave up their time to participate in the deliberative research project.

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